

Impact of Specialized Pediatric Palliative Care: A Systematic Review

Supplementary Material

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This supplementary material has been provided by authors to give readers additional information about their work.

Table A1. Search Strategy

Full terms of search strategy (covering 2000-June 2018)

Database: PubMed	
ID	Query
#70	Search (#68 AND #69)
#69	Search ((Randomized Controlled Trial[pt] OR Interrupted Time Series Analysis[Mesh] OR Randomised[tiab] OR Randomized[tiab] OR Experiment*[tiab] OR Time series[tiab] OR Interrupted Time[tiab] OR Pre test[tiab] OR Pretest[tiab] OR Post test[tiab] OR Posttest[tiab] OR Impact[tiab] OR Intervention*[tiab] OR Change*[tiab] OR Evaluat*[tiab] OR Effect*[tiab] OR Compar*[tiab] OR Cohort Studies[Mesh] OR Cohort*[tiab] OR Case-Control Studies[Mesh] OR Case Control[tiab] OR Before After[tiab] OR Before During[tiab]) NOT (Animal[Mesh] NOT Human[Mesh]))
#68	Search (#18 AND #34 AND #55 AND #67)
#67	Search (#56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65 OR #66)
#66	Search Satisfact*[tiab]
#65	Search Patient Satisfaction[Mesh]
#64	Search Distress[tiab]
#63	Search Suffer*[tiab]
#62	Search Pain*[tiab]
#61	Search Pain[Mesh]
#60	Search Wellbeing[tiab]
#59	Search Well Being[tiab]
#58	Search Life Quality[tiab]
#57	Search "Quality of Life"[tiab]
#56	Search Quality of Life[Mesh]
#55	Search (#35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53 OR #54)
#54	Search Toddler*[tiab]
#53	Search Young[tiab]
#52	Search Youth*[tiab]
#51	Search Teens[tiab]
#50	Search Teenage*[tiab]
#49	Search Adolescen*[tiab]
#48	Search Adolescent[Mesh]
#47	Search Babies[tiab]
#46	Search Child*[tiab]
#45	Search Paediatric*[tiab]
#44	Search Pediatric*[tiab]
#43	Search Prematur*[tiab]
#42	Search Preterm*[tiab]
#41	Search Newborn*[tiab]
#40	Search Neonat*[tiab]

#39	Search Still Birth*[tiab]
#38	Search Stillbirth*[tiab]
#37	Search Stillbirth[Mesh]
#36	Search Infant*[tiab]
#35	Search Infant[Mesh]
#34	Search (#19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32 OR #33)
#33	Search Hospice*[tiab]
#32	Search Hospices[Mesh]
#31	Search Hospice Care[Mesh]
#30	Search Spiritual Support[tiab]
#29	Search Emotional Support[tiab]
#28	Search Bereavement Support[tiab]
#27	Search Psychosocial Support[tiab]
#26	Search Supportive Care*[tiab]
#25	Search Compassionate Care*[tiab]
#24	Search Terminal Care*[tiab]
#23	Search Terminal Care[Mesh]
#22	Search Palliat*[tiab]
#21	Search Palliative Medicine[Mesh]
#20	Search (Hospice and Palliative Care Nursing[Mesh])
#19	Search Palliative Care[Mesh]
#18	Search (#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17)
#17	Search Care Needs[tiab]
#16	Search Cancer[tiab]
#7	Search Serious Ill*[tiab]
#15	Search Complex Condition*[tiab]
#14	Search "End of Life"[tiab]
#13	Search Terminally Ill*[tiab]
#12	Search Terminally Ill[Mesh]
#11	Search Dying[tiab]
#10	Search End Stage*[tiab]
#9	Search Life Limit*[tiab]
#8	Search Life Threat*[tiab]
#6	Search Critically Ill[tiab]
#5	Search Critical Ill*[tiab]
#4	Search Critical Illness[Mesh]
#3	Search Chronic Condition*[tiab]
#2	Search Chronic Disease*[tiab]
#1	Search Chronic Diseases[Mesh]
#1	MeSH descriptor: [Chronic Disease] explode all trees
#2	Chronic Disease*:ti,ab,kw (Word variations have been searched)

- #3 Chronic Condition*:ti,ab,kw (Word variations have been searched)
- #4 MeSH descriptor: [Critical Illness] explode all trees
- #5 Critical Ill*:ti,ab,kw (Word variations have been searched)
- #6 Critically Ill:ti,ab,kw (Word variations have been searched)
- #7 Life Threat*:ti,ab,kw (Word variations have been searched)
- #8 Life Limit*:ti,ab,kw (Word variations have been searched)
- #9 End Stage*:ti,ab,kw (Word variations have been searched)
- #10 Dying:ti,ab,kw (Word variations have been searched)
- #11 MeSH descriptor: [Terminally Ill] explode all trees
- #12 Terminally Ill:ti,ab,kw (Word variations have been searched)
- #13 "End of Life":ti,ab,kw (Word variations have been searched)
- #14 Complex Condition*:ti,ab,kw (Word variations have been searched)
- #15 Serious Ill*:ti,ab,kw (Word variations have been searched)
- #16 Cancer:ti,ab,kw (Word variations have been searched)
- #17 Care Needs:ti,ab,kw (Word variations have been searched)
- #18 #1 or #2 or #3 or #4 or #5 or #6 or #7 or #8 or #9 or #10 or #11 or #12 or #13 or #14 or #15 or #16 or #17
- #19 MeSH descriptor: [Palliative Care] explode all trees
- #20 MeSH descriptor: [Hospice and Palliative Care Nursing] explode all trees
- #21 MeSH descriptor: [Palliative Medicine] explode all trees
- #22 Palliat*:ti,ab,kw (Word variations have been searched)
- #23 MeSH descriptor: [Terminal Care] explode all trees
- #24 Terminal Care*:ti,ab,kw (Word variations have been searched)
- #25 Compassionate Care*:ti,ab,kw (Word variations have been searched)
- #26 Supportive Care*:ti,ab,kw (Word variations have been searched)
- #27 Psychosocial Support:ti,ab,kw (Word variations have been searched)
- #28 Bereavement Support:ti,ab,kw (Word variations have been searched)
- #29 Emotional Support:ti,ab,kw (Word variations have been searched)
- #30 Spiritual Support:ti,ab,kw (Word variations have been searched)
- #31 MeSH descriptor: [Hospice Care] explode all trees
- #32 MeSH descriptor: [Hospices] explode all trees
- #33 Hospice*:ti,ab,kw (Word variations have been searched)
- #34 #19 or #20 or #21 or #22 or #23 or #24 or #25 or #26 or #27 or #28 or #29 or #30 or #31 or #32 or #33
- #35 MeSH descriptor: [Infant] explode all trees
- #36 Infant*:ti,ab,kw (Word variations have been searched)
- #37 MeSH descriptor: [Stillbirth] explode all trees
- #38 Stillbirth*:ti,ab,kw (Word variations have been searched)
- #39 Still Birth*:ti,ab,kw (Word variations have been searched)
- #40 Neonat*:ti,ab,kw (Word variations have been searched)
- #41 Newborn*:ti,ab,kw (Word variations have been searched)
- #42 Preterm*:ti,ab,kw (Word variations have been searched)
- #43 Prematur*:ti,ab,kw (Word variations have been searched)
- #44 Pediatric*:ti,ab,kw (Word variations have been searched)

#45 Paediatric*:ti,ab,kw (Word variations have been searched)
 #46 Child*:ti,ab,kw (Word variations have been searched)
 #47 Babies:ti,ab,kw (Word variations have been searched)
 #48 MeSH descriptor: [Adolescent] explode all trees
 #49 Adolescen*:ti,ab,kw (Word variations have been searched)
 #50 Teenage*:ti,ab,kw (Word variations have been searched)
 #51 Teens:ti,ab,kw (Word variations have been searched)
 #52 Youth*:ti,ab,kw (Word variations have been searched)
 #53 Young:ti,ab,kw (Word variations have been searched)
 #54 Toddler*:ti,ab,kw (Word variations have been searched)
 #55 #35 or #36 or #37 or #38 or #39 or #40 or #41 or #42 or #43 or #44 or #45 or #46 or #47 or #48 or
 #49 or #50 or #51 or #52 or #53 or #54
 #56 MeSH descriptor: [Quality of Life] explode all trees
 #57 "Quality of Life":ti,ab,kw (Word variations have been searched)
 #58 Life Quality:ti,ab,kw (Word variations have been searched)
 #59 Well Being:ti,ab,kw (Word variations have been searched)
 #60 Wellbeing:ti,ab,kw (Word variations have been searched)
 #61 MeSH descriptor: [Pain] explode all trees
 #62 Pain*:ti,ab,kw (Word variations have been searched)
 #63 Suffer*:ti,ab,kw (Word variations have been searched)
 #64 Distress:ti,ab,kw (Word variations have been searched)
 #65 MeSH descriptor: [Patient Satisfaction] explode all trees
 #66 Satisfact*:ti,ab,kw (Word variations have been searched)
 #67 #56 or #57 or #58 or #59 or #60 or #61 or #62 or #63 or #64 or #65 or #66
 #68 #18 and #34 and #55 and #67
 #69 #67 AND #68

 'randomized-controlled-trial'/exp OR 'randomized-controlled-trial' OR 'randomization'/exp OR
 'randomization' OR 'controlled-study'/exp OR 'controlled-study' OR 'multicenter study'/exp OR
 'multicenter study' OR 'phase-3-clinical-trial'/exp OR 'phase-3-clinical-trial' OR 'phase-4-clinical-
 trial'/exp OR 'phase-4-clinical-trial' OR 'double-blind-procedure'/exp OR 'double-blind-procedure' OR
 'single blind-procedure'/exp OR 'single blind-procedure' OR random*:ab,ti OR placebo*:ab,ti OR
 #68 volunteer*:ab,ti OR (singl*:ab,ti OR doubl*:ab,ti OR trebl*:ab,ti OR tripl*:ab,ti AND (blind*:ab,ti OR
 mask*:ab,ti)) OR 'interrupted time':ti,ab OR 'time series':ti,ab OR experiment*:ti,ab OR 'pre test':ti,ab
 OR pretest:ti,ab OR 'post test':ti,ab OR posttest:ti,ab OR impact:ti,ab OR intervention*:ti,ab OR
 change*:ti,ab OR evaluat*:ti,ab OR effect*:ti,ab OR comparar*:ti,ab OR 'cohort analysis'/exp OR
 'cohort analysis' OR cohort*:ti,ab OR 'case control study'/exp OR 'case control study' OR 'case
 control':ti,ab OR 'before after':ti,ab OR 'before during':ti,ab NOT ('animals'/exp OR 'animals' NOT
 ('humans'/exp OR 'humans' AND ('animals'/exp OR 'animals')))

 #67 #18 AND #33 AND #54 AND #66
 #66 #55 OR #56 OR #57 OR #58 OR #59 OR #60 OR #61 OR #62 OR #63 OR #64 OR #65
 #65 satisfact*:ti,ab
 #64 'patient satisfaction'/exp
 #63 distress:ti,ab
 #62 suffer*:ti,ab

#61	pain*:ti,ab
#60	'pain'/exp
#59	'wellbeing':ti,ab
#58	'well being':ti,ab
#57	'life quality':ti,ab
#56	'quality of life':ti,ab
#55	'quality of life'/exp
#54	#34 OR #35 OR #36 OR #37 OR #38 OR #39 OR #40 OR #41 OR #42 OR #43 OR #44 OR #45 OR #46 OR #47 OR #48 OR #49 OR #50 OR #51 OR #52 OR #53
#53	toddler*:ti,ab
#52	young*:ti,ab
#51	youth*:ti,ab
#50	teens:ti,ab
#49	teenage*:ti,ab
#48	adolescen*:ti,ab
#47	'adolescent'/exp
#46	babies:ti,ab
#45	child*:ti,ab
#44	paediatric*:ti,ab
#43	pediatric*:ti,ab
#42	prematu*:ti,ab
#41	preterm*:ti,ab
#40	newborn*:ti,ab
#39	neonat*:ti,ab
#38	'still birth':ti,ab
#37	stillbirth*:ti,ab
#36	'stillbirth'/exp
#35	infant*:ti,ab
#34	'infant'/exp
#33	#19 OR #20 OR #21 OR #22 OR #23 OR #24 OR #25 OR #26 OR #27 OR #28 OR #29 OR #30 OR #31 OR #32
#32	hospice*:ti,ab
#31	'hospice'/exp
#30	'hospice care'/exp
#29	'spiritual support':ti,ab
#28	'emotional support':ti,ab
#27	'bereavement support':ti,ab
#26	'psychosocial support':ti,ab
#25	'supportive care':ti,ab OR 'supportive cares':ti,ab
#24	'compassionate care':ti,ab OR 'compassionate cares':ti,ab
#23	'terminal care':ti,ab OR 'terminal cares':ti,ab
#22	'terminal care'/exp
#21	palliat*:ti,ab

#20	'palliative nursing'/exp
#19	'palliative therapy'/exp
#18	#1 OR #2 OR #3 OR #4 OR #5 OR #6 OR #7 OR #8 OR #9 OR #10 OR #11 OR #12 OR #13 OR #14 OR #15 OR #16 OR #17
#17	'care needs':ti,ab
#16	'cancer':ti,ab
#15	'serious ill':ti,ab OR 'serious illness':ti,ab
#14	'complex condition':ti,ab OR 'complex conditions':ti,ab
#13	'end of life':ti,ab
#12	'terminally ill':ti,ab
#11	'terminally ill patient'/exp
#10	'dying':ti,ab
#9	'end stage':ti,ab OR 'end stages':ti,ab
#8	'life limit':ti,ab OR 'life limits':ti,ab
#7	'life threat':ti,ab OR 'life threats':ti,ab
#6	'critically ill':ti,ab
#5	'critical illness':ti,ab
#4	'critical illness'/exp
#3	'chronic condition':ti,ab OR 'chronic conditions':ti,ab
#2	'chronic disease':ti,ab OR 'chronic diseases':ti,ab
#1	'chronic disease'/exp
S96	S66 AND S95
S95	S67 OR S68 OR S69 OR S70 OR S71 OR S72 OR S73 OR S74 OR S75 OR S76 OR S77 OR S78 OR S79 OR S80 OR S81 OR S82 OR S83 OR S84 OR S85 OR S86 OR S87 OR S88 OR S89 OR S90 OR S91 OR S92 OR S93 OR S94
S94	TI Before During OR AB Before During
S93	TI Before After OR AB Before After
S92	TI Case Control OR AB Case Control
S91	(MH "Case Control Studies+")
S90	TI Cohort* OR AB Cohort*
S89	TI Compar* OR AB Compar*
S88	TI Effect* OR AB Effect*
S87	TI Change* OR AB Change*
S86	TI Intervention* OR AB Intervention*
S85	TI Impact OR AB Impact
S84	TI Posttest OR AB Posttest
S83	TI Post test OR AB Post test
S82	TI Pretest OR AB Pretest
S81	TI Pre test OR AB Pre test
S80	TI Interrupted Time OR AB Interrupted Time
S79	TI Time series OR AB Time series
S78	TI Experiment* OR AB Experiment*
S77	(MM "Interrupted Time Series Analysis")
S76	TX allocat* random*

S75	(MH "Placebos")
S74	TX placebo*
S73	TX random* allocat*
S72	(MH "Random Assignment")
S71	TX randomi* control* trial*
S70	TX ((singl* n1 blind*) or (singl* n1 mask*)) or TX ((doubl* n1 blind*) or (doubl* n1 mask*)) or TX ((tripl* n1 blind*) or (tripl* n1 mask*)) or TX ((trebl* n1 blind*) or (trebl* n1 mask*))
S69	TX clinic* n1 trial*
S68	PT Clinical trial
S67	(MH "Clinical Trials+")
S66	S18 AND S33 AND S53 AND S65
S65	S54 OR S55 OR S56 OR S57 OR S58 OR S59 OR S60 OR S61 OR S62 OR S63 OR S64
S64	TI Satisfact* OR AB Satisfact*
S63	(MM "Patient Satisfaction")
S62	TI Distress OR AB Distress
S61	TI Suffer* OR AB Suffer*
S60	TI Pain* OR AB Pain*
S59	(MH "Pain+")
S58	TI Wellbeing OR AB Wellbeing
S57	TI Well Being OR AB Well Being
S56	TI Life Quality OR AB Life Quality
S55	TI "Quality of Life" OR AB "Quality of Life"
S54	(MH "Quality of Life+")
S53	S34 OR S35 OR S36 OR S37 OR S38 OR S39 OR S40 OR S41 OR S42 OR S43 OR S44 OR S45 OR S46 OR S47 OR S48 OR S49 OR S50 OR S51 OR S52
S52	TI Toddler* OR AB Toddler*
S51	TI Young OR AB Young
S50	TI Youth* OR AB Youth*
S49	TI Teens OR AB Teens
S48	TI Teenage* OR AB Teenage*
S47	TI Adolescen* OR AB Adolescen*
S46	(MH "Adolescence+")
S45	TI Babies OR AB Babies
S44	TI Child* OR AB Child*
S43	TI Paediatric* OR AB Paediatric*
S42	TI Pediatric* OR AB Pediatric*
S41	TI Prematur* OR AB Prematur*
S40	TI Preterm* OR AB Preterm*
S39	TI Newborn* OR AB Newborn*
S38	TI Neonat* OR AB Neonat*
S37	TI Still Birth* OR AB Still Birth*
S36	TI Stillbirth* OR AB Stillbirth*
S35	TI Infant* OR AB Infant*

S34	(MH "Infant+")
S33	S19 OR S20 OR S21 OR S22 OR S23 OR S24 OR S25 OR S26 OR S27 OR S28 OR S29 OR S30 OR S31 OR S32
S32	TI Hospice* OR AB Hospice*
S31	(MM "Hospices")
S30	(MM "Hospice Care")
S29	TI Spiritual Support OR AB Spiritual Support
S28	TI Emotional Support OR AB Emotional Support
S27	TI Bereavement Support OR AB Bereavement Support
S26	TI Psychosocial Support OR AB Psychosocial Support
S25	TI Supportive Care* OR AB Supportive Care*
S24	TI Compassionate Care* OR AB Compassionate Care*
S23	TI Terminal Care* OR AB Terminal Care*
S22	(MH "Terminal Care+")
S21	TI Palliat* OR AB Palliat*
S20	(MM "Hospice and Palliative Nursing")
S19	(MM "Palliative Care")
S18	S1 OR S2 OR S3 OR S4 OR S5 OR S6 OR S7 OR S8 OR S9 OR S10 OR S11 OR S12 OR S13 OR S14 OR S15 OR S16 OR S17
S17	TI Care Needs OR AB Care Needs
S16	TI Cancer OR AB Cancer
S15	TI Serious Ill* OR AB Serious Ill*
S14	TI Complex Condition* OR AB Complex Condition*
S13	TI "End of Life" OR AB "End of Life"
S12	TI Terminally Ill OR AB Terminally Ill
S11	(MH "Terminally Ill Patients+")
S10	TI Dying OR AB Dying
S9	TI End Stage* OR AB End Stage*
S8	TI Life Limit* OR AB Life Limit*
S7	TI Life Threat* OR AB Life Threat*
S6	TI Critically Ill OR AB Critically Ill
S5	TI Critical Ill* OR AB Critical Ill*
S4	(MM "Critical Illness")
S3	TI Chronic Condition* OR AB Chronic Condition*
S2	TI Chronic Disease* OR AB Chronic Disease*
S1	(MM "Chronic Disease")

Table A2. Measuring risk of bias for patient reported outcome measures (PROMs)

When assessing risk of bias, PROMs are classically penalized because of the risks for recall and social desirability bias among others.(1) Given that the patient and caregiver's experience are the essence of what palliative care looks to impact on and based on recent recommendations on how to use PROs in systematic reviews,(2) we developed a system to evaluate risk of bias when a PROM was used. Table A2 below summarizes the approach. Risk of bias was categorized as low, unclear or high according to whether authors used self-, caregiver-, or clinician-reported outcomes, and the degree of validation of the instrument used (formally validated, non-formally validated but commonly used, and developed ad hoc for the study). Thus, lower risk was assigned to studies that used self-report and a validated instrument whereas higher risk was assigned when outcomes were reported by clinicians (or abstracted from the medical record) using an ad-hoc tool.

Table A2. Risk of bias assessment for patient reported outcomes				
		Who reports?		
		Self-reported	Caregiver	Clinician
Instrument characteristics	Validated			
	Non-validated commonly used			
	Ad hoc			

Low risk Unclear Risk High risk

REFERENCES

1. Higgins JPT, Green S, editores. Cochrane Handbook for Systematic Reviews of Interventions Version 5.1.0 [updated March 2011]. The Cochrane Collaboration; 2011.
2. Johnston BC, Patrick DL, Busse JW, Schünemann HJ, Agarwal A, Guyatt GH. Patient-reported outcomes in meta-analyses--Part 1: assessing risk of bias and combining outcomes. Health Qual Life Outcomes. 1 de julio de 2013;11:109.

Table A3. Description of the intervention/exposure

In Table A3, we summarize the description of the intervention/exposure as provided by the different papers.

Table A3. Characteristics of the SPPC intervention/exposure as described in papers			
Study	SPPC team	Setting and Activities	Frequency
Chong (2018)	(+) Home-based SPPC service consisting of 1 SPPC MD, 4 pediatric nurses, 2 social workers, and 1 administrative executive.	(+/-) Provision of home and inpatient consults; 24/7 support provided by a mixed adult-pediatric service.	(-)
Fraser (2013)	(+) Hospice-based SPPC service; full-time SPPC consultant.	(+/-) Provision of home visits and inpatient care; 24/7 on-call medical service.	(-)
Friedrichsdorf (2015)	(+) Palliative home care and/or home hospice care; SPPC nurses, social workers, child life specialists, chaplaincy, SPPC physician.	(+) SPPC provided regularly scheduled visits depending on clinical needs (See frequency) and were available 24/7 for home visits. SPPC nurses assessed distressing symptoms, coordinated with prescribing physicians, and offered care coordination, nursing care, and psycho-social-spiritual care. The social workers undertook regular home visits as well as phone contact to provide the entire family with counseling and support while assisting with community resources, as well as bereavement support. The child life specialist worked with siblings for memory making as well as offered and undertook school visits to meet with teachers and students in how to deal with a student at end of life. The chaplain provided emotional, spiritual, and bereavement support to the child and family.	(+) Regularly -from several times per day to once per month, on average weekly- scheduled visits depending on clinical needs.
Gans (2015)	(+) SPPC program contracting with nurses and social workers at multiple hospice and home health agencies across 11 counties.	(+) The care coordinators complete a formal evaluation regularly to ensure that the family's needs and goals are at the forefront of decisions about the child's care. Formal evaluations are reviewed by the referring physician. The care coordinator contacts the family regularly and often accompanies the caregiver on visits to physicians and/or to conferences at the child's school. Children receive pain and symptom management and expressive therapies including art, music, play, and massage. Families receive education, including instruction on providing care and operating medical equipment, counseling and bereavement services, access to a 24/7 on-call hospice or home health agency nurse, and respite care in and out of the home to provide needed rest for primary caregivers.	(+) Formal evaluation at least every 60 days. The care coordinator contacts the family at least monthly.

Table A3. Characteristics of the SPPC intervention/exposure as described in papers (cont.)			
Study	SPPC team	Setting and Activities	Frequency
Golan (2008)	(+) Oncology-based SPPC team (PCT) in a pediatric palliative and terminal care unit (PCU). Full-time SPPC nurses work with interdisciplinary oncology staff, which includes oncologists, social workers, psychologists, creative art/child life specialists, nutritionists, physical therapists, and spiritual advisor.	(+) SPPC nurses provide ambulatory and inpatient care at PCU, home visits, and bereavement follow-up. For each new patient admitted to the Pediatric Hematology Oncology Department chances for cure and prognosis are estimated by a multidisciplinary team. Poor prognosis patients (anticipated cure <30%) are introduced to the PCT, and have priority for hospitalization in the PCU. The PCT continues to follow the PP patients on an ambulatory basis, during hospitalizations in other departments and at home. Hospitalizations in the PCU are in agreement with the family, as well as the agreement not to perform resuscitation in the terminal phase. After the patient's death, bereavement support is provided, and includes visits, phone calls and grief workshops for family members.	(-)
Goldhagen (2016)	(+) Community-based SPPC program providing medical, nursing, social work, child life, spiritual, and volunteer services.	(+) Services include pain and symptom management; medical consultation; mental health, psychosocial and spiritual support and counseling; family respite; assistance with financial issues and resource development; case management and care coordination; and bereavement and grief support. Special attention is also paid to the needs of the siblings.	(-)
Groh (2013)	(+) Home-based SPPC consisting of 3 pediatricians, 2 nurses, social worker, chaplain, all trained in SPPC.	(+/-) Main tasks of the team are provision of palliative medical and nursing care, including a 24/7 on-call service, as well as psychosocial support and coordination of professional assistance in cooperation with the local Health Care Professionals.	(-)
Gupta (2013)	(+) Community-based SPPC program consisting of nurses, clinical psychology, palliative care support workers, cultural development worker, bereavement support worker.	(-)	(-)
Hancock (2018)	(+) Community-based service consisting of 3 community pediatric nurses and 2 part-time child psychologists, supported by hospital-based consultants and senior nurse managers.	(+) In this study, the initial palliative care consultation did not vary from any other SPPC consultation performed in the hospital and occurred when the neonate was admitted for planned surgery – following birth but before the first-stage palliative surgery (only intervention patients). In addition to the provision of comfort-focused end-of-life care, a standardized form was completed by a designated SPPC team provider asking the mother about 10 specific areas. This information was used by the SPPC team to provide support and recommendations, determine frequency and duration of follow-up visits, and content of subsequent interactions.	(+) Initial palliative care consultation (duration of 45–90 minutes). 1 to 4 Follow-up visits (30-minute visits per week).

Table A3. Characteristics of the SPPC intervention/exposure as described in papers (cont.)			
Study	SPPC team	Setting and Activities	Frequency
Hays (2006)	(+) Hospital-based multidisciplinary team consisting of physicians, advanced practice nurses, social worker, benefits coordinator and co-case managers (local hospice nurses).	(+) SPPC team implemented 3 major program components: 1) clinical decision-making; 2) provider education on pain and symptom management, end of life care, and ethical decision-making; and 3) flexible administration of benefits and co-case management. The SPPC team worked with a set of pain and symptom management algorithms specifically designed to address the needs. The responsibility for ongoing care, including pain and symptom management, continued to reside with the medical team, either specialty or primary care, who referred the patient to the project. The project physicians and nurses often provided advice but did not assume care and thus did not interrupt the ongoing relationships that existed between patients and their medical caregivers. The project staff facilitated all care conferences and produced the documentation that was used by the families, medical teams and insurance plans as the ongoing plan of care.	(+/-) 18 months follow up post enrollment or death, whichever occurred first.
Horrocks (2002)	(+) Community-based service consisting of 3 community pediatric nurses and 2 part-time child psychologists, supported by hospital-based consultants and senior nurse managers.	(-)	(-)
Kassam (2015)	(-) Hospital-based SPPC team, no further details provided.	(-)	(-)
Keele (2013)	(-) Hospital-based SPPC characteristics vary by site.	(-)	(-)
Osenga (2016)	(+) Hospital-based SPPC; SPPC physician and nurses, social workers, child life specialists, chaplaincy, music therapy.	(+/-) Provision of home care (within 35 miles), outpatient clinic, and inpatient setting, with 24/7 physician and advanced practice nurse consults available.	(-)
Petteys (2015)	(+) Hospital-based SPPC service consisting of advanced practice nurse and registered nurse with extensive NICU experience, both trained in SPPC; additional medical support as needed.	(+) The PC nurses provided continuity of care for NICU infants/families; PC services also included assessments (of both infants and parents), interdisciplinary collaboration and care coordination. Specific activities included: coordination of family conferences, provided or requested orders to improve infant symptom management and comfort, and addressed parental coping and self-care.	(+/-) At least PC nurses provided weekly verbal parent support.

Table A3. Characteristics of the SPPC intervention/exposure as described in papers (cont.)			
Study	SPPC team	Setting and Activities	Frequency
Pierucci (2001)	(+) Hospital-based SPPC consultation service consisting of 2 clinical nurse specialists and a physician medical director.	(+) SPPC nurses participate, by working directly with the existing medical team and the patient's family, making recommendations about the environment, advanced directive planning, medical interventions, and emotional support as the families cope with grief and bereavement. SPPC nurses report to the supervising PPC physician regarding consultation requests and recommendations; physician does not become involved unless specifically requested to by the primary physician. The decision to implement any recommendations is made by the patient's attending physician. Once consulted, the palliative care staff follows the patient with the medical team for the duration of the admission. If the patient does not die during the hospitalization, then the palliative care service participates in discharge planning and home care through consultation with a home care agency. Whether the patient dies at home or in the hospital, the palliative care staff often help with funeral arrangements and bereavement counseling.	(-)
Postier (2014)	(+) Hospital-based SPPC. Palliative/hospice home services include nurses, social workers, child life specialists, chaplains, music/massage therapists, physicians, and volunteers.	(+/-) 24/7 access and care coordination across children's medical and wider community (e.g., school) through home-based visits.	(-)
Schmidt (2013)	(-) No details provided on specific SPPC state teams.	(-)	(-)
Smith (2015)	(+) Hospital-based SPPC service consisting of medical director, advanced practice nurse, registered nurse, social worker, interfaith chaplain.	(+/-) Formal PPC consultation consists of an initial interdisciplinary team assessment with ongoing inpatient and outpatient follow-up. Referrals for PPC are made by the patient's primary inpatient team or by family request (no predefined criteria for referrals exist). PPC consultation was defined as intervention by all or part of the interdisciplinary PPC team in which discussion of goals of care, benefits and burdens of proposed treatments, quality of life, advance care planning, code status, communication, psychosocial and spiritual distress, or symptom management were addressed.	(-)
Snaman (2017)	(-) Hospital-based SPPC team, no details provided.	(-)	(-)
Ullrich (2016)	(+) Hospital-based SPPC team consists of physician, nurse, social worker.	(+) SPPC team provides inpatient, outpatient, and home-based consultations and ongoing education to pediatric oncology practitioners. PPC consultation activities included assessment and recommendations on the following topics: "goals of care," decision-making/advance care planning," "symptom management," and "support for the child and family, including psychosocial and spiritual support, home services, and quality of life."	(+/-) Median follow-up SPPC team visits for inpatients: 8 over 3 months. Outpatient visits much less frequent (summary measure not provided).

Table A3. Characteristics of the SPPC intervention/exposure as described in papers (cont.)			
Study	SPPC team	Setting and Activities	Frequency
Vern-Gross (2015)	(-) Hospital-based SPPC interdisciplinary program, no further details provided	(+) SPPC team conducts ongoing assessments to identify patient and family preferences, goals, and needs throughout a child's illness during consultations, regular inpatient/outpatient follow-up, team meetings, and home visits. SPPC offered symptom management expertise, addressed psychosocial and spiritual needs throughout the continuum of care, coordinated care, and ensured communication between providers at times of transition, facilitated end-of-life/do-not-resuscitate discussions, and provided decision-making and bereavement support. SPPC offers hospice support services for patients and families returning to their home institutions.	(-)
Widger (2017)	(-) Hospital-based SPPC team, no details provided.	(-)	(-)
Wolfe (2008)	(+) Hospital-based SPPC team, consult team typically involves a physician, nurse, and social worker	(+) SPPC clinicians provide ongoing education about palliative care to pediatric oncology practitioners through rounds, a monthly interdisciplinary case-based conference, and discipline-specific educational sessions. SPPC provides clinical consultations to the medical team and the patient and/or family in the inpatient, outpatient, and home settings. SPPC consults delineate goals of care with the primary team and family; subsequent recommendations stem from these goals. SPPC clinicians have led efforts to develop system-wide improvements such as a direct admission policy, which allows dying children to be admitted directly to the oncology ward, rather than first being attended to in the emergency department, and the comfort corner, a home-like suite on the inpatient oncology ward.	(-)

Abbreviations=NICU: neonatal intensive care unit; **SPPC**: specialized pediatric palliative care; **PCT**: palliative care team; **PCU**: palliative care unit; **PPC**: pediatric palliative care; **PC**: palliative care.

Classification of team, setting and activities and frequency descriptions= **SPPC team**: +, at least describes team members/ -, no team description; **Setting and activities**: +, at least some description of both setting and activities/ +/- at least some description of either setting or activities / -, no description of activities; **Frequency**: + describes minimal frequency of SPPC visits / +/-, provides frequency of some SPPC activities but not of SPPC visits, or data is incomplete / -, no mention of the frequency of SPPC activities.